

DMH Satisfaction Survey Results

Consumer Satisfaction - 2001

Family Directed Support

Introduction

Missouri's Family Directed Supports (MFDS) was established in July, 1998, by the Missouri Division of Mental Retardation and Developmental Disabilities as part of an overall system redesign initiative aimed at supporting families caring for a member with a developmental disability in their home. Incorporating the values and principles of family support, Missouri's Family Directed Supports emphasizes the responsibility and authority of families in planning, developing, and accessing the unique supports they need.

The survey looked at the impact of the Family Directed Support program on families. The purpose of the survey was to solicit opinions from participants as to how the program has affected their family. The second portion of the survey asked families to describe other issues or events that impact on their family's life. This report will describe the findings of the survey.

Methodology

All families that received services under the Family Directed Support program (4165 families) were mailed survey forms. Seven hundred three forms were returned, for a return rate of 16.9%.

Demographics of the Sample

The survey looked at the age of the family member who was receiving services, the relationship of the person who completed the survey to the consumer, and whether a Support Agreement had been approved or signed. There were many instances where the respondent did not complete the demographic information. The frequencies of these demographics will be presented.

Gender of Recipient

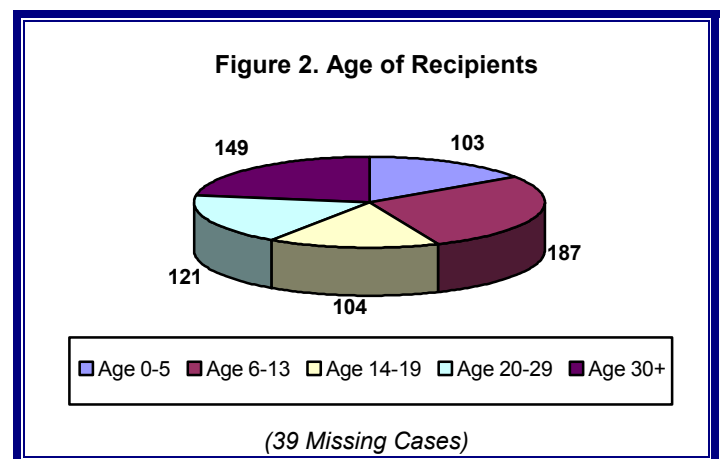
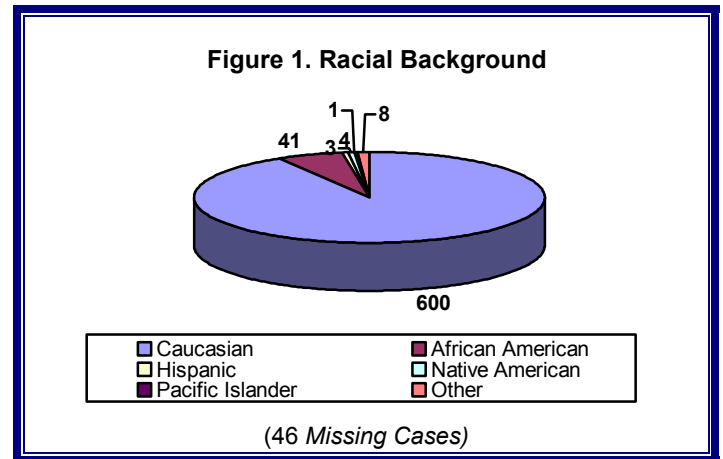
Families reported more males served (60.6%) than females (39.4%).

Racial Background

The majority of the families were Caucasian (91.3%). There were 41 families (6.2%) who were African American, 4 families (0.6%) who were Hispanic, 3 families (0.5%) who were Native American, 1 family (0.1%) who were Pacific Islanders and 8 families who noted an "other" racial background (1.2%). (See Figure 1.)

Age of the Recipient

The age of the family member was listed on the form. When two family members' ages were listed, the oldest was used. The mean age was 19.50 years. Figure 2 presents the age distribution.



Satisfaction with Services

Overall both families in the regular Division of MR/DD sample and in the FDS (Family Directed Support) sample were satisfied with the services (means of 4.30 and 3.96 respectfully). Families in the MR/DD only group were most satisfied with the staff's respect of ethnic and cultural backgrounds while the FDS families were most satisfied with the staff keeping information confidential. Families in both groups were least satisfied with services being provided in a timely manner. See Table 1.

Table 1 - Satisfaction with Services (Part 1)

How happy are you . . .	Albany (MRDD only)	Albany (FDS only)	Central (MRDD only)	Central (FDS only)	Hannibal (MRDD only)	Hannibal (FDS only)	Joplin (MRDD only)	Joplin (FDS only)	Kansas City (MRDD only)	Kansas City (FDS only)	Kirksville (MRDD only)	Kirksville (FDS only)
1. with the people who are paid to support your family member?	4.78 (9)	4.20 (49)	4.33 (3)	4.26 (39)	4.41 (17)	4.28 (29)	4.56 (9)	4.31 (35)	4.13 (31)	3.98 (42)	4.30 (10)	4.18 (40)
2. with how much your family member's support staff know about how to get things done?	4.78 (9)	4.22 (49)	4.50 (2)	3.97 (39)	4.35 (17)	4.19 (32)	4.67 (9)	4.26 (34)	4.10 (30)	3.84 (45)	4.30 (10)	4.12 (41)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	4.78 (9)	4.55 (51)	4.33 (3)	4.48 (33)	4.53 (17)	4.72 (32)	4.57 (7)	4.54 (35)	4.26 (31)	4.43 (42)	4.60 (10)	4.24 (42)
4. that your family member's plan has what he/she wants in it?	4.67 (9)	4.10 (51)	4.00 (3)	4.06 (35)	4.06 (16)	4.15 (33)	4.63 (8)	4.29 (35)	4.15 (27)	3.83 (42)	4.33 (9)	4.09 (43)
5. with how the case manager and support people are doing what your family member's plan says they should do?	4.78 (9)	3.98 (52)	4.00 (2)	4.05 (39)	4.13 (16)	4.33 (33)	4.75 (8)	4.26 (35)	4.13 (31)	3.76 (45)	4.30 (10)	4.17 (42)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	4.75 (8)	4.31 (45)	4.33 (3)	4.45 (33)	4.38 (16)	4.71 (28)	4.57 (7)	4.52 (31)	4.47 (30)	4.36 (39)	4.56 (9)	4.39 (38)
7. with the supports and services that your family member receives from this Regional Center?	4.67 (9)	4.04 (52)	4.00 (4)	4.08 (38)	4.12 (17)	4.47 (34)	4.67 (9)	4.26 (35)	4.24 (29)	3.80 (45)	4.80 (10)	4.38 (45)
8. that services to your family member are provided in a timely manner?	4.67 (9)	3.96 (52)	4.33 (3)	3.95 (40)	4.00 (15)	4.12 (33)	4.44 (9)	4.06 (34)	4.07 (30)	3.62 (45)	4.40 (10)	4.19 (43)
9. with your family member's case manager?	4.67 (9)	4.44 (52)	4.00 (4)	4.08 (39)	4.29 (17)	4.48 (33)	4.78 (9)	4.34 (35)	4.27 (30)	3.86 (44)	4.60 (10)	4.45 (44)
The first number represents a mean rating. Scale: 1=Not at all satisfied . . . 5=Very satisfied. The number in parentheses represents the number responding to this item.												

Table 1 - Satisfaction with Services (Part 2)

How happy are you . . .	Poplar Bluff (MRDD only)	Poplar Bluff (FDS only)	Rolla (MRDD only)	Rolla (FDS only)	Sikeston (MRDD only)	Sikeston (FDS only)	Springfield (MRDD only)	Springfield (FDS only)	St. Louis (MRDD only)	St. Louis (FDS only)	Total State (MRDD only)	Total State (FDS only)
1. with the people who are paid to support your family member?	-	4.22 (37)	4.17 (12)	3.81 (42)	4.50 (6)	4.29 (31)	4.67 (9)	3.65 (40)	4.18 (22)	4.05 (248)	4.33 (128)	4.08 (632)
2. with how much your family member's support staff know about how to get things done?	-	3.92 (36)	3.92 (13)	3.64 (44)	4.50 (6)	4.24 (33)	4.88 (8)	3.65 (40)	4.08 (26)	3.72 (253)	4.28 (130)	3.89 (646)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	-	4.16 (37)	4.25 (12)	4.09 (45)	4.67 (6)	4.60 (35)	4.44 (9)	4.22 (37)	4.48 (27)	4.32 (244)	4.45 (131)	4.36 (633)
4. that your family member's plan has what he/she wants in it?	-	4.06 (35)	4.33 (12)	3.67 (45)	4.17 (6)	4.29 (34)	4.50 (8)	3.53 (38)	4.44 (25)	3.72 (253)	4.32 (123)	3.89 (644)
5. with how the case manager and support people are doing what your family member's plan says they should do?	-	3.89 (37)	3.92 (12)	3.78 (46)	4.17 (6)	4.23 (35)	5.00 (9)	3.80 (41)	4.30 (27)	3.84 (255)	4.30 (130)	3.94 (660)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	-	4.43 (35)	4.33 (12)	4.02 (41)	4.50 (4)	4.58 (31)	4.88 (8)	4.22 (37)	4.59 (27)	4.28 (237)	4.52 (124)	4.34 (595)
7. with the supports and services that your family member receives from this Regional Center?	-	4.21 (38)	3.92 (13)	3.96 (45)	4.33 (6)	4.17 (35)	4.56 (9)	3.58 (40)	4.18 (28)	3.78 (268)	4.30 (134)	3.96 (675)
8. that services to your family member are provided in a timely manner?	-	3.97 (38)	3.93 (14)	3.67 (46)	4.00 (6)	4.11 (36)	4.56 (9)	3.49 (41)	4.14 (28)	3.49 (270)	4.19 (133)	3.74 (678)
9. with your family member's case manager?	-	4.16 (38)	4.00 (12)	4.00 (46)	4.50 (6)	4.28 (36)	4.56 (9)	4.10 (41)	4.26 (27)	3.94 (262)	4.35 (133)	4.11 (670)
<p>The first number represents a mean rating.</p> <p>Scale: 1=Not at all satisfied . . . 5=Very satisfied.</p> <p>The number in parentheses represents the number responding to this item.</p>												

Satisfaction with Quality of Life

Families in the MR/DD only group were most satisfied with where their family member lives while the FDS families were most satisfied with safety in the home. Families in the MR/DD only group were least satisfied with how their family member spends his/her spare time while the FDS families were least satisfied with the opportunities/chances their family member had to make friends. See Table 2.

Table 2 - Satisfaction with Quality of Life (Part 1)

How happy are you . . .	Albany (MRDD only)	Albany (FDS only)	Central (MRDD only)	Central (FDS only)	Hannibal (MRDD only)	Hannibal (FDS only)	Joplin (MRDD only)	Joplin (FDS only)	Kansas City (MRDD only)	Kansas City (FDS only)	Kirksville (MRDD only)	Kirksville (FDS only)
10. with how your family member spends his/her day?	4.44 (9)	3.74 (50)	3.75 (4)	4.26 (38)	3.93 (15)	4.15 (33)	4.33 (9)	4.14 (35)	4.19 (31)	3.98 (43)	4.30 (10)	4.14 (44)
11. with where your family member lives?	4.67 (9)	4.73 (49)	4.25 (4)	4.46 (35)	4.65 (17)	4.68 (34)	4.88 (8)	4.59 (34)	4.37 (30)	4.73 (41)	4.40 (10)	4.28 (43)
12. with the number of choices your family member has in his/her life?	4.44 (9)	3.72 (50)	4.00 (4)	4.11 (35)	3.94 (16)	3.94 (34)	4.38 (8)	3.94 (34)	4.18 (28)	3.88 (42)	4.30 (10)	3.79 (42)
13. with the opportunities/chances your family member has to make friends?	4.44 (9)	3.53 (51)	3.75 (4)	4.06 (36)	3.81 (16)	3.88 (33)	4.13 (8)	3.74 (31)	4.11 (27)	3.63 (43)	4.44 (9)	3.98 (45)
14. with your family member's health care?	4.67 (9)	4.33 (51)	4.00 (4)	4.13 (39)	4.12 (17)	4.21 (33)	4.56 (9)	4.21 (34)	4.10 (29)	4.26 (42)	4.40 (10)	4.16 (44)
15. with what your family member does during his/her free time?	4.44 (9)	3.63 (51)	4.00 (3)	3.89 (35)	3.88 (16)	4.00 (32)	3.78 (9)	3.81 (32)	3.97 (29)	3.77 (43)	4.20 (10)	4.00 (44)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	4.44 (9)	3.96 (49)	4.33 (3)	4.03 (35)	3.80 (15)	4.09 (32)	4.25 (8)	4.06 (31)	4.07 (28)	4.13 (39)	4.50 (8)	3.85 (39)
How safe do you feel ...												
17. your family member is in his/her home?	4.67 (9)	4.75 (52)	4.67 (3)	4.44 (39)	4.38 (16)	4.57 (35)	4.78 (9)	4.77 (35)	4.43 (28)	4.67 (45)	4.75 (8)	4.44 (45)
18. your family member is in his/her neighborhood?	4.56 (9)	4.38 (52)	4.67 (3)	4.18 (40)	4.27 (15)	4.26 (35)	4.50 (8)	4.54 (35)	4.21 (28)	4.38 (45)	4.86 (7)	4.41 (46)
The first number represents a mean rating. Scale: (<i>how satisfied are you...</i>): 1=Not at all satisfied . . . 5=Very satisfied. Scale: (<i>how safe do you feel...</i>): 1=Not at all safe . . . 5=Very safe. The second number represents the number responding to this item.												

Table 2 - Satisfaction with Quality of Life (Part 2)

How happy are you . . .	Poplar Bluff (MRDD only)	Poplar Bluff (FDS only)	Rolla (MRDD only)	Rolla (FDS only)	Sikeston (MRDD only)	Sikeston (FDS only)	Springfield (MRDD only)	Springfield (FDS only)	St. Louis (MRDD only)	St. Louis (FDS only)	Total State (MRDD only)	Total State (FDS only)
10. with how your family member spends his/her day?	-	4.08 (37)	4.07 (14)	3.60 (45)	4.00 (6)	4.15 (34)	4.67 (9)	3.51 (41)	4.15 (27)	3.73 (264)	4.19 (134)	3.87 (664)
11. with where your family member lives?	-	4.53 (36)	4.23 (13)	4.27 (45)	4.67 (6)	4.67 (33)	4.78 (9)	4.38 (37)	4.43 (28)	4.33 (261)	4.49 (134)	4.45 (648)
12. with the number of choices your family member has in his/her life?	-	3.97 (35)	3.69 (13)	3.44 (45)	3.83 (6)	3.87 (31)	4.50 (8)	3.54 (41)	4.19 (27)	3.56 (257)	4.14 (129)	3.71 (646)
13. with the opportunities/ chances your family member has to make friends?	-	3.74 (34)	3.75 (12)	3.51 (45)	4.00 (6)	3.97 (30)	4.83 (6)	3.33 (42)	3.96 (27)	3.43 (260)	4.07 (124)	3.60 (650)
14. with your family member's health care?	-	4.14 (35)	3.93 (14)	4.05 (44)	4.17 (6)	4.38 (34)	4.56 (9)	3.95 (42)	4.29 (28)	4.02 (262)	4.24 (135)	4.12 (660)
15. with what your family member does during his/her free time?	-	3.74 (34)	4.00 (14)	3.55 (44)	3.83 (6)	4.00 (31)	4.67 (6)	3.63 (41)	4.04 (27)	3.42 (257)	4.04 (129)	3.64 (644)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	-	3.91 (32)	3.75 (12)	3.56 (41)	4.33 (6)	4.00 (31)	4.83 (6)	3.65 (40)	4.04 (27)	3.76 (246)	4.12 (122)	3.85 (615)
How safe do you feel ...												
17. your family member is in his/her home?	-	4.70 (37)	4.17 (12)	4.43 (46)	4.00 (6)	4.60 (35)	4.56 (9)	4.67 (39)	4.57 (28)	4.44 (268)	4.48 (128)	4.54 (676)
18. your family member is in his/her neighborhood?	-	4.49 (37)	4.08 (12)	4.11 (46)	4.00 (6)	4.36 (33)	4.71 (7)	4.26 (39)	4.57 (28)	4.05 (263)	4.40 (123)	4.22 (671)
<p>The first number represents a mean rating. Scale: (<i>how satisfied are you...</i>): 1=Not at all satisfied . . . 5=Very satisfied. Scale: (<i>how safe do you feel...</i>): 1=Not at all safe . . . 5=Very safe. The second number represents the number responding to this item.</p>												

Impact of the Program on Family Life

The family members were asked to rate how their life had changed in each of fifteen areas as a result of their participation in Missouri's Family Directed Support Program. The families were asked to rate this change on a five point scale (1=*a lot worse*; 2=*a little worse*; 3=*no change*; 4=*a little better*; 5=*a lot better*). Means were calculated for each of the responses as well as the frequency distribution of the responses.

Overall

One question asked how their family's life overall had changed. The mean for this item was 4.03. Seventy-five percent of those who responded reported that their life was at least *a little better*. Over one-third of the respondents noted that it was *a lot better* (33.3%). (See Figure 3.)

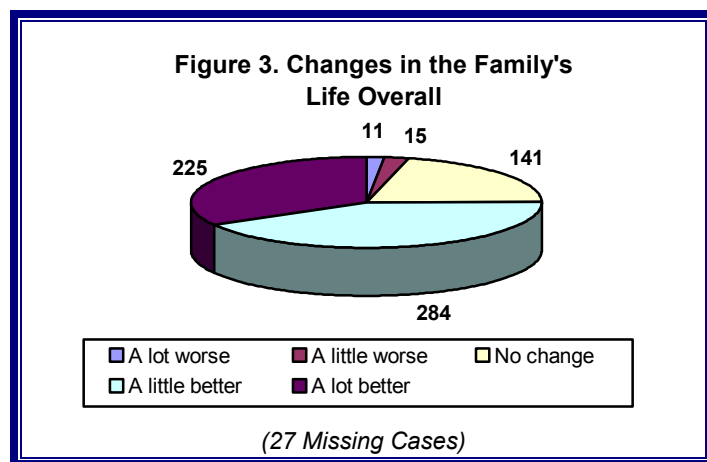
Family Functioning

Four items examined the ability of the family to function. These included (1) family's ability to do more together; (2) the stress in the family's life; (3) the family's ability to be more like other families; and (4) financial worries. Table 3 presents the results.

Table 3. Changes in Family Functioning

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your Family's ability to do more together	14 (2.1%)	13 (1.9%)	241 (35.8%)	223 (31.7%)	182 (25.9%)	3.81
The stress in your family's life	28 (4.1%)	38 (5.6%)	185 (27.3%)	252 (37.2%)	174 (25.7%)	3.75
Your family's ability to be more like other families	22 (3.3%)	16 (2.4%)	263 (39.1%)	230 (34.2%)	142 (21.1%)	3.67
Your financial worries	39 (5.8%)	42 (6.3%)	240 (35.8%)	209 (31.1%)	141 (21.0%)	3.55

^aScale: 1 = a lot worse.....5 = a lot better



The item with the highest mean was the family's ability to do more together. This item showed a mean change of 3.81, indicating that it was *a little better* than before. The other items in this category were also slightly improved for at least 50% of the respondents. All of these items showed similar change.

The means for the respondents of each Regional Center were calculated. (See Table 4.)

Table 4. Regional Center Means of Changes in Family Functioning

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family's ability to do more together	3.83 (52)	3.82 (44)	3.83 (35)	4.00 (45)	4.00 (35)	3.59 (39)
The stress in your family's life	3.60 (52)	3.89 (44)	3.83 (35)	4.04 (46)	3.71 (35)	3.80 (40)
Your family's ability to be more like other families	3.69 (51)	3.61 (44)	3.83 (35)	3.76 (46)	3.97 (35)	3.54 (39)
Your financial worries	3.63 (51)	3.67 (43)	3.60 (35)	3.73 (45)	3.69 (35)	3.40 (40)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family's ability to do more together	3.77 (44)	4.00 (36)	4.19 (36)	3.72 (268)	3.72 (39)	3.81 (673)
The stress in your family's life	3.71 (45)	3.74 (35)	3.97 (36)	3.69 (268)	3.59 (41)	3.75 (677)
Your family's ability to be more like other families	3.67 (45)	3.86 (37)	3.94 (36)	3.58 (264)	3.56 (41)	3.67 (673)
Your financial worries	3.64 (45)	3.57 (37)	4.11 (36)	3.42 (264)	3.40 (40)	3.55 (671)
^a Scale: 1 = a lot worse.....5 = a lot better						

Caring for Family Member

The survey looked at the ability of the family to care for the family member. There were two items that related to this category: (1) ability to care for family member; and (2) worries about family member's future well being (see Table 5 for the results).

Table 5. Changes in Caring for Family Member

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your ability to care for your family member	16 (2.4%)	17 (2.5%)	167 (24.9%)	254 (37.9%)	217 (32.3%)	3.95
Your worries about your family member's future well being	35 (5.2%)	48 (7.1%)	220 (32.7%)	243 (36.2%)	126 (18.8%)	3.56
^a Scale: 1 = a lot worse.....5 = a lot better						

The families perceived at least a slight change for the better on the first of these items. For the item about caring for their family member, 32.3% noted *a lot better* situation now. For worrying about their family member's future well being, only 18.8% of the respondents noted a lot of improvement.

The means by Regional Center were calculated for changes in caring for family members.

Table 6. Regional Center Means of Changes in Caring for Family Member

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your ability to care for your family member	4.02 (49)	3.95 (43)	4.09 (35)	4.16 (45)	4.23 (35)	3.92 (39)
Your worries about your family member's future well being	3.65 (52)	3.86 (43)	3.54 (35)	3.80 (46)	3.77 (35)	3.50 (40)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your ability to care for your family member	3.96 (45)	3.81 (37)	4.29 (35)	3.83 (266)	3.95 (42)	3.95 (671)
Your worries about your family member's future well being	3.59 (44)	3.59 (37)	4.00 (35)	3.40 (264)	3.34 (41)	3.56 (672)
^a Scale: 1 = a lot worse.....5 = a lot better						

Families' Ability to Do Activities

The literature has often reported that families of individuals with developmental disabilities have more difficulty maintaining a social life. The survey looked at several items that related to this category. First was the family's ability to do things that they were unable to do before. The second related to the family's ability to get to know other people in the community. The third item focused on the family's level of inclusion in the community (see Table 7).

Table 7. Changes in the Families' Ability to do Activities

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean ^a
Your ability to do things that you were unable to do before	15 (2.2%)	21 (3.1%)	240 (35.9%)	236 (35.3%)	157 (23.5%)	3.75
Your ability to get to know other people in your community	13 (1.9%)	12 (1.8%)	360 (53.3%)	188 (27.8%)	103 (15.2%)	3.53
Your family's level of inclusion in the community	18 (2.7%)	18 (2.7%)	365 (54.6%)	176 (26.3%)	92 (13.8%)	3.46
^a Scale: 1 = a lot worse.....5 = a lot better						

The Family Support Program had a larger impact on the families' ability to do things they were unable to do before than the other categories. Nearly 60% of the respondents noted that this had changed for the better since participating in the program. The item that showed the least amount of positive change was the family's level of inclusion in the community. Here only 13.8% noted that it was *a lot better*.

Table 8. Regional Center Means of Changes in the Families' Ability to do Activities

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your ability to do things that you were unable to do before	3.76 (51)	3.79 (42)	3.74 (35)	3.74 (46)	4.26 (34)	3.60 (40)
Your ability to get to know other people in your community	3.54 (52)	3.77 (44)	3.77 (35)	3.41 (46)	3.69 (35)	3.43 (40)
Your family's level of inclusion in the community	3.57 (51)	3.70 (43)	3.57 (35)	3.37 (46)	3.60 (35)	3.45 (40)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your ability to do things that you were unable to do before	3.76 (45)	3.69 (36)	4.09 (34)	3.67 (267)	3.67 (39)	3.75 (669)
Your ability to get to know other people in your community	3.60 (45)	3.62 (37)	3.70 (33)	3.41 (268)	3.56 (41)	3.53 (676)
Your family's level of inclusion in the community	3.55 (44)	3.54 (37)	3.62 (34)	3.38 (264)	3.15 (40)	3.46 (669)
<i>°Scale: 1 = a lot worse.....5 = a lot better</i>						

Family's Well Being

There were two items on the survey that related to the family's well being. One concerned their emotional well being and the other their physical health (see Table 9).

Table 9. Changes in the Family's Well Being

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean°
Your family's emotional well being	20 (3.0%)	32 (4.8%)	237 (35.3%)	239 (35.6%)	143 (21.3%)	3.68
Your family's physical well being	14 (2.1%)	27 (4.0%)	344 (51.3%)	164 (24.5%)	121 (18.1%)	3.52
<i>°Scale: 1 = a lot worse.....5 = a lot better</i>						

The respondents noted a larger positive change in their emotional well being than in their physical health. The mean of the former was 3.68, with 57% noting a change for the better, while the latter mean was 3.52, with only 42% reporting this change.

Table 10. Regional Center Means of Changes in Family's Well Being

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family's emotional well being	3.71 (52)	3.79 (43)	3.77 (35)	3.70 (46)	3.74 (34)	3.60 (40)
Your family's physical well being	3.37 (51)	3.70 (43)	3.83 (35)	3.54 (46)	3.65 (34)	3.55 (40)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family's emotional well being	3.67 (45)	3.84 (37)	4.00 (35)	3.58 (264)	3.65 (40)	3.68 (671)
Your family's physical well being	3.51 (45)	3.41 (37)	3.85 (33)	3.44 (266)	3.55 (40)	3.52 (670)
<i>°Scale: 1 = a lot worse.....5 = a lot better</i>						

Family Members' Well Being

The program affected the family member's level of inclusion in the community less than their emotional well-being and growth and development. (See Table 11).

Table 11. Changes in the Family Members' Well Being

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your family members' emotional well being	18 (2.7%)	31 (4.6%)	220 (32.6%)	240 (35.6%)	165 (24.5%)	3.75
Your family members' level of inclusion in the community	23 (3.4%)	17 (2.5%)	318 (47.5%)	209 (31.2%)	103 (15.4%)	3.53
Your family members' growth and development	23 (3.4%)	22 (3.3%)	194 (29.0%)	261 (39.0%)	169 (25.3%)	3.79
^a Scale: 1 = a lot worse.....5 = a lot better						

Many of the families reported no change occurring in these items. This was particularly true for the family members' community inclusion. Here, over 45% of the families reported no change with an additional 6% reporting a negative impact.

Table 12. Regional Center Means of Changes in Family Members' Well Being

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family member's emotional well being	3.71 (52)	3.95 (43)	3.94 (35)	3.87 (46)	3.91 (35)	3.78 (40)
Your family member's level of inclusion in the community	3.58 (52)	3.72 (43)	3.74 (35)	3.54 (46)	3.51 (35)	3.63 (40)
Your family member's growth and development	3.82 (51)	4.05 (44)	3.89 (35)	3.87 (46)	3.74 (35)	3.60 (40)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family member's emotional well being	3.69 (45)	3.92 (37)	3.80 (35)	3.65 (266)	3.55 (40)	3.75 (674)
Your family member's level of inclusion in the community	3.40 (45)	3.68 (37)	3.56 (32)	3.45 (265)	3.45 (40)	3.53 (670)
Your family member's growth and development	3.68 (44)	3.95 (37)	4.00 (33)	3.75 (265)	3.62 (39)	3.79 (669)
^a Scale: 1 = a lot worse.....5 = a lot better						

Impact of Age of Family Member on Responses

An analysis was conducted to determine if the age of the family member was related to the responses of the family. The age of the family member was divided into two categories: (1) those under 21 years of age; and (2) those 21 years of age and older. There was no significant responses based on age (see Table 13).

Table 13. Comparison of Responses by Age of the Family Member^a

Item:	Children/Youth	Adults	Significance
Your family's life overall	4.03 (398)	4.03 (238)	-
Your family's ability to do more together	3.77 (398)	3.86 (236)	-
Your stress in your family's life	3.73 (400)	3.77 (238)	-
Your family's ability to be more like other families	3.64 (399)	3.71 (234)	-
Your ability to care for your family member	3.93 (396)	3.98 (235)	-
Your financial worries	3.52 (397)	3.61 (235)	-
Your worries about your family members' future well being	3.52 (396)	3.63 (237)	-
Your ability to do things that you were unable to do before	3.70 (396)	3.82 (234)	-
Your ability to get to know other people in your community	3.45 (398)	3.61 (239)	-
Your family's level of inclusion in the community	3.39 (398)	3.54 (232)	-
Your family's emotional well being	3.66 (396)	3.68 (235)	-
Your family's physical health	3.50 (396)	3.56 (234)	-
Your family members' emotional well being	3.74 (399)	3.77 (236)	-
Your family members' level of inclusion in the community	3.49 (397)	3.55 (234)	-
Your family members' growth and development	3.82 (396)	3.74 (233)	-
^a Scale: 0 = a lot worse.....4 = a lot better			

Other Issues or Events that Impact the Family's Life

One question asked the families to identify other issues that impacted their family's life. This item was interpreted differently by many of the respondents. Many felt that it was related to the program and many others reported about their own personal life or that of their child. This section will describe the subjective responses to this question.

Positive Responses

There were many responses that were quite positive about the program and did not discuss other issues or events that impacted the family's life. Some of those responses are listed here.

- *Daily lives are effected by Autism - lots of stress - FDS has been a positive to allow us not to have stress re: providing treatment for our son and support for our family.*

- *I'm happy. My coordinator pops in from time to time at my son's school. DMH sat in on my son's IEP meeting and I know he got the things he needed because they were there. I can't thank them enough.*
- *Our child needs constant 1-on-1 supervision. FDS has helped her be more inclusive in our community and has given her a much happier life.*
- *Everyone does their jobs so well that there is very little effort required on my part to have my son in the program. I have been very well informed with each step. All involved have been most considerate of our needs.*
- *The genuine interest that staff have shown and kindness and personality of support staff helping with computer etc.*

Issues with Support Staff

While the Family Directed Support Program was seen as helping many aspects of the family's life, there were some new issues related to support staff.

Some contracted services not satisfactory. Staff came in - not realizing the situation they had to work with - level of care - type of care, etc.

There appeared to several people to be a lack of respite care providers. *No backup providers when we're sick or no school. Not enough respite providers to relieve the PC's so as not to burn them out.* Another person said *there is a need in our area for trained and experienced respite caregivers that can come to families' homes for respite regularly.* Another comment was made regarding group home respite. *Not enough group home respite time offered. Group home always says "can't take respite due to unstaffing".*

One family's issue with support staff was with the lack of pay for the staff. *I feel that the people that work with my daughter needs to be "paid higher" wages. It is hard to find/get good qualified people to work with special needs kids and one way to keep them is to pay a decent wage.*

Transportation

Transportation has been an issue for many years for families and consumers in the Missouri Department of Mental Retardation/Developmental Disabilities. It continues to plague many families. There were a number of responses related to transportation. *Living in small town at least 25 miles away from everything and having to find rides when needing or wanting to go places.* Another person stated *transportation is virtually zero in C... County for someone who cannot drive.* One family said they would like to take family member on trips and vacation, but a car is not good for his travel. *Needs to be able to lay down about 1/3 to 1/2 the time.*

Timelines of Signed Agreement

Some of the families saw the process of obtaining a signed agreement as taking too long. *I feel that her life has been more fulfilled through her plan for she is now in Girl Scouts and meeting young teens her age. I feel that they need to get the plans done faster and quit restricting what they can have on the plans.*

Financial Assistance

One family wanted financial assistance for their daughter. *Our insurance is fighting us all the way. Our daughter is very healthy so she can't qualify for any assistance because of her good health and our financial category! I think it is very frustrating! I can't even qualify for respite care. I pay thousands of dollars a year in taxes to support all these programs, yet my daughter can't receive any of them! How sad!* A few families reported having financial worries. Some families listed what they wanted the financial assistance for. *We are trying to locate funding for a will and special needs trust to be written for K.* Another family wanted *the financial ability to access what's "available" for education and therapeutic NEEDS.*

Some families had personal financial issues that went beyond the family member. *My daughter has numerous appts. in St. Louis, this has forced me to miss work many times over the last year. This has effected my family financially.* Other concerns were *with limited income it's hard to financially do a lot of outings, van repairs and recreational.* Another family had *financial concerns for medical bills or equipment.*

For some families, it is not financial worry that was the issue, but rather guarding their funds for their family member. *Concern over exceeding our daughter's life time limit in our health insurance as well as how to estate plan.*

Learning About Resources and Support Groups

For many families, keeping up to date with new information, knowing what resources are available, and what support groups are out there, would be very helpful. One person suggested *local programs to help keep family up to date with changes in the laws, maybe through the local school district.* Many families wanted support groups. *It would be nice to have a parents group or annual meeting or something to get area families together to share experiences.* Another person said they would like to have a system to encourage interaction between "like" families. *Start bowling teams or picnic activities so MRDD folks can make friends with peers.* One person needed *sibling support to help them deal with our disabled child better (counseling, outside activities).* Some people commented on how much the support groups have helped them. *The support group in our area is very helpful. Especially the bowling and swimming trips.*

Lack of Follow-Through

Some families reported that while there were plans in place, there was a lack of follow through on carrying out the activities of the plan. *Why develop a plan - spend the \$\$ to develop a plan and etc. Then not follow the plan. What a joke! FDS in this area isn't at all like it was supposed to be!* Another person said *My son was supposed to be helped so he would be able to function on his own. The only thing ever done was he was instructed in cooking about 5 times. Keeping house was never discussed or budgeting!*

Health Issues

There were a number of responses that indicated that the family had health issues either of the child or a family member. For one family it was *Our son's recurrent health problems and the stress it puts on our family. Medical bills from 2000 (helicopter ride to hospital). One person was unable to find dental care for child that accepts Medicaid.* Another echoed that statement by saying *there is no insurance for doctors or medical cards.* One person's daughter *has not been able to go to the specialist doctor's because of "fund" problems.*

For some families, the health issue was with the parents or caregiver. *The unaffordable health care for myself - Scares me for my son's future. I need a dentist really bad.* Another person was afraid of not being able to care for their child as they age. *Our aging and health has created some difficulty in caring for our daughter, and as time goes by, we realize we'll need even more physical aids and probably changes in the home (mainly bathroom) to enable us to continue to care for her.*

Public Awareness

A need was seen for more public awareness on the part of the public, be it teachers or social workers. *Attitudes. People don't know how to react to people with disabilities. They ignore or make harsh judgment on people who don't have obvious disabilities.* Another person's concern was with *other peoples understanding of my situation. Most people do not understand what my daughter is going through or her disabilities so therefore they tend to be critical of me.*

Community Activities

For some families, community activities were lacking in their son or daughter's life. *There are not enough interaction or programs to keep them busy enough for friendship and exercise. Being active would decrease some of their health problems.* Another person said *Our son is mildly mentally retarded and has Cerebral Palsy. He is extremely lonely. There are few social occasions that he can participate in (2 in the past year) and no support groups to deal with the loneliness, and the things he can't do such as date/drive.* Another parent echoed this by saying *Sometimes without supports he is unable to participate in activities that neuro typical kids can participate.* One parent shared their frustrations. *I recently updated my sons story and had asked for a family pool membership for \$180.00 for the whole family. It also gave my son*

social and sensory needs to be met, but it was declined because it was for the whole family. I thought the program was call MO Family Directed Support. This was something we could do all as a family. Another parent listed activities that had a positive effect on their child and also offered some recommendations. Challenger Sports, Autism Symposiums & Seminars, Respite, Day-Camp, Week-long camp, Horseback riding therapy. (Would love to have music and art therapy included in these and possibly dance lessons.) As my child grows his interests and needs change.

Transition

Some families worried about the transition of their child when they aged. Need placement - we are elderly and worry what will happen when we're gone. Another said As my daughter approaches age 18, I worry about the matter of guardianship, such as the cost involved and having it in place with no time gaps in case of a medical emergency. I also worry about her care if I become incapacitated and the legal issues of trying to set up a fund for her without it affecting her future SSI.

Problems with Schools

Many families shared similar frustrations regarding the schools their children attend. I am not happy with his school or area that we live in. I need to work again and move out of my area for a better future. Another person said I worry a lot about his schooling. My son is Autistic and 15 years old. They do not have an appropriate program provided at the school! Another parent voiced similar concerns regarding her daughter. Currently having problems at school. Doesn't seem like her disability was taken into consideration. Not much the caseworker could do. Another parent tried to find a good preschool program for her son. Finding an appropriate preschool for my son. Our school system was very intent on not providing appropriate services. One parent wanted more opportunities for an older child and suggested an in-between school for high functioning Autistic between high school and college.

Church

Many families noted how much their church has helped them. A good church positively makes impact with my family's life. Another person said We are regular church members. My daughter participates in youth choir, plays, etc. She also is a participant of Special Olympics and Exceptional Equestrians.

Free Time

Several people commented that they appreciate having more free time because of the Family Directed Support program. Allows us to do things during the day we would not get to do otherwise. Another person said they appreciated Time away from son. Help me to be better mother to my son. He needs to be away from me also. Less stress. A positive male role model for my son. One parent was happy to have more time with other family members. As his parent, I now have more time for other family members. He is also learning how to manage on his own. But the cost of maintenance still puts burden on parents. Some parents

feel like they have no free time at all. *My husband and I have no private life anymore. She never leaves the house except once a month with Home Health aide to shop at Wal-Mart. Another person said Part of our problem is the multiplicity of members with handicaps in our family. It helps a lot to receive services for each one but rarely do they coincide to give us real free time.*

Behavior Problems

Some parents struggled with their child's behavior. *Her behavior is disruptive at times and very hard to handle physically and emotionally. Another person said Our child is receiving an in-home behavioral program called ABA. Our son has been in this program for 12 months and is very stressful on each family member in different ways. One person noted a change in behavior Aunt M. does not like to do things around the house since she has started going to day care.*

Heavy Lifting

A few people needed extra assistance with heavy lifting. *Heavy lifting is involved. We need people who can lift. Another person said they need someone who can lift. To put in bed - on pot and in wheelchair.*

Sarah J Lopez waiver

One person said *We receive help from the Sarah J. Lopez waiver. We feel extremely fortunate that we receive it, but very frustrated that few people in this area know anything about it, therefore they do not want to put forth the effort to help us use it (they try to think of other ways to pay for services that are already taken care of through the waiver, because they do not want to learn how to use the waiver).*